

Assessing New York State's Response to COVID-19 for People with Intellectual and Developmental Disabilities

Prepared by the Developmental Disabilities Advisory Council
With Assistance from the New York State Developmental
Disabilities Planning Council



November 2022

Report Cover Art Contest

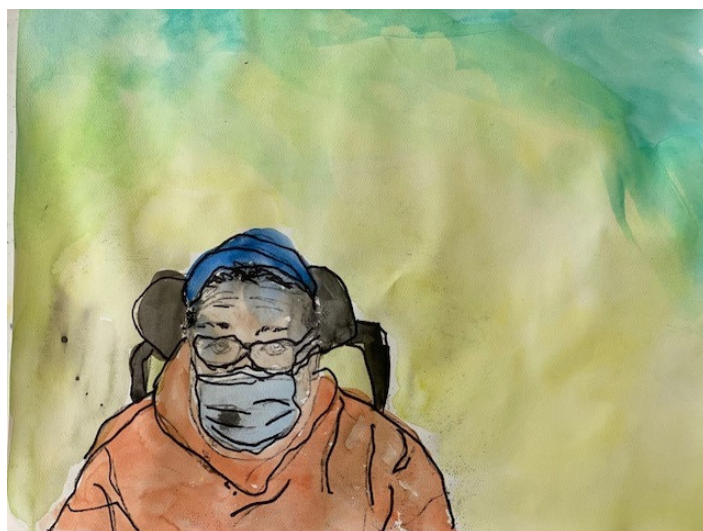
The Developmental Disabilities Advisory Council, in partnership with New York State Senator John W. Mannion, sponsored an art contest for self-advocates to feature COVID-19-related art on the cover of this report. More than 40 self-advocates from across New York State submitted art work. Congratulations to the winner, **Austin Cortez (front cover)** and runners-up, featured below. To see a gallery of artwork from all the artists, visit www.ddpc.ny.gov.



Art by Monica Mzese



Art by Jason Valles



Art by Bob Pitts

ABOUT THE DEVELOPMENTAL DISABILITIES ADVISORY COUNCIL

The Developmental Disabilities Advisory Council (DDAC) was established pursuant to section 13.05 of New York State Mental Hygiene Law and is comprised of Governor-appointed volunteers from various stakeholder groups. They provide recommendations for statewide priorities and goals, comprehensive planning, resource allocation, and evaluation processes for state and local services for people with developmental disabilities.

DDAC Members:

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Find out more at: opwdd.ny.gov/developmental-disabilities-advisory-council-ddac

WITH ASSISTANCE FROM

**THE NEW YORK STATE DEVELOPMENTAL
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**Developmental Disabilities
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About the Report

On December 21, 2021, Governor Kathy Hochul signed New York State (NYS) Senate Bill S.6294A into law requiring the Developmental Disabilities Advisory Council (DDAC) to look at how the state responded to COVID-19 for people with intellectual and developmental disabilities (IDD).

The law included two major tasks:

1. Review the state's response to COVID-19.
2. Provide recommendations to the NYS Legislature and Governor to improve the state's response for people with IDD during future emergencies.

The NYS Developmental Disabilities Planning Council (DDPC) helped the DDAC prepare this report.

For a full version of this report, visit www.ddpc.ny.gov

Methods of Analysis:

- Conducted research
- Reviewed guidance and policies
- Reviewed outreach to stakeholders
- Reviewed pandemic related costs
- Analyzed data
- Sent out online surveys
- Held focus groups

1,500 family member
survey responses

+

450 self-advocate survey
responses

+

33 focus groups with
250 participants

=

2,200
stakeholders
providing
input

The NYS Response to COVID-19

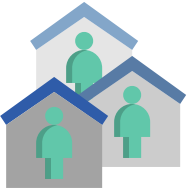
NYS responded to COVID-19 for people with IDD in many ways including:



Providing Personal Protective Equipment (PPE), such as masks and gloves, to state operated facilities



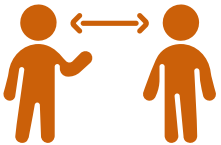
Testing and vaccinations for people with IDD living in and staff working in congregate settings



Isolating people with IDD infected with COVID-19 living in group homes and other congregate settings



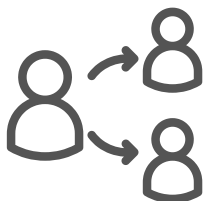
Temporary closure of day programs



Temporary ending of visits in group homes and other congregate settings

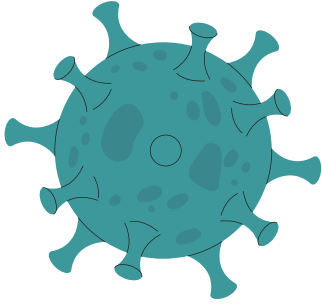


Rules around hospital visitation and discharge



Meeting with the IDD community to talk about pandemic rules and get feedback. Some changes were made to the rules as a result of this feedback.

Impact of COVID-19 on People with IDD

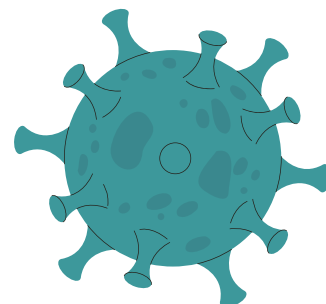


From March 2020 through March 2021, more than 10,000 people supported by OPWDD services tested positive for COVID-19 and close to 650 died as a result.

People with IDD living in group homes or other certified settings were four times more likely to test positive for COVID-19 and two times more likely to die as a result when compared to the general population.

More people with IDD were infected and died from COVID-19 because they also had other health conditions.

About 30% of people with IDD in New York lived in a group home or other certified setting; however, they made up 86% of COVID-19 deaths of people receiving OPWDD services.



How was NYS' Response for People with IDD?

After careful review of data and certain guidance from the state, the DDAC had several questions.



Could the state have done anything to give guidance more quickly to keep up with the changing pandemic?



Did the state miss opportunities to plan ahead during the summer when there were less new cases, knowing an approved vaccine was coming?



Did the state keep visitation and other restrictions in place for too long as the pandemic was improving?



Could the state have better communicated with all stakeholders?



Could the state have provided more support to residential providers?



Could the state have been more helpful in finding local testing and vaccination centers for people with IDD and staff?

What People with IDD and Family Members Said



People with IDD in the community and their family members felt ignored.



Some found it hard to find and understand health and safety rules.



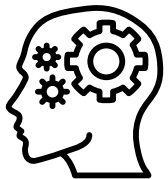
Wearing a mask was hard for some people with IDD and, at times, stopped them from getting health care.



Sometimes, family members needed to care for their loved ones with IDD because of less staff and the closing of day programs. This caused stress if the family member was sick, an essential worker or working from home.



Some family caregivers thought that they should have been one of the first groups to get the vaccine. Some areas of the state had accessible vaccination sites, but some did not.



The mental health of people with IDD, their family caregivers and staff became worse during the pandemic.



No visits in group homes and other facilities made people with IDD and their family members worried and sad. Some did not agree with the rules.



It was hard for some people with IDD to use virtual services, and not all services were helpful.

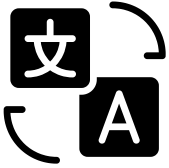
"The state operated residences always got preferential treatment over those of us living at home or in a non-group setting."

- Self-advocate

What Underserved Communities Said



Underserved communities were almost all ignored.



Health and safety rules were not in plain language in English or other languages.



People with IDD living in underserved communities and their family members counted on community-based organizations to give them information, not the state.



The state could have used communication tools that people living in underserved communities prefer to use, such as ethnic radio, to share information.



People with IDD in underserved communities and their families had a hard time getting internet and computers to participate in virtual services.

An underserved community is a community that includes people from minority populations or people with less resources and services.

What Providers and Care Coordination Organizations (CCOs) Said

- At times, the state did not issue health and safety guidance in a timely way to address the needs of people with IDD in congregate settings.
- The state was not clear if the same rules that applied to nursing homes also applied to group homes. This caused confusion and frustration.
- The state did very little to help providers and CCOs get PPE.
- It was hard for providers to make staff get the vaccine.
- Some providers could not follow quarantine rules because of the size or layout of their buildings, or they did not have enough staff.
- Providers worried that the requirement to take people with no COVID-19 symptoms back from hospitals made other people sick.
- The pandemic made the shortage of staff worse.
- Flexibilities provided by the state helped providers have enough money and continued services for people with IDD.
- The tracking system for COVID-19 data was difficult for providers to maintain and took a lot of time.

**"Chaotic, confusing and scary quite frankly."
- Provider's description of the state's response**

Recommendations



Create an emergency management plan just for the IDD community

- Include the IDD community in the COVID-19 review RFP issued by the Governor's Office on July 20, 2022.
- Make health and safety rules easy to understand and easy to get, especially for people with IDD in underserved communities. Give the rules to providers and CCOs as soon as possible.
- Think of the IDD community's needs when making rules about visitation, hospital discharge, vaccinations, testing, mask wearing and quarantining.
- Create a plan to keep services going for people in the IDD community including people in the community or with special needs like being medically fragile.
- Work with local emergency management offices to make a plan to meet the needs of the IDD community.
- Train first responders to understand and respond to the special needs of the IDD community during a public emergency.
- Make data collection easier and improve access to data during an emergency.

Recommendations



Address systemic issues made worse by the pandemic.

- Improve coordination between NYS agencies and local government offices during a public emergency.
- Increase staffing to support people with IDD.
- Make other housing options in the community more available for people with IDD.
- Keep waivers to continue flexibility for providers and offer more flexibility to people with IDD who self-direct.
- Help people with IDD use the internet, get computers and access online programs and services.
- Partner with organizations to improve communication with underserved communities.
- Promote the mental wellness of people with IDD, family caregivers and the IDD workforce.

Additional Areas of Concern

The DDAC found more areas of concern while making this report. The DDAC asks Governor Hochul and the NYS Legislature to think about the following questions:

1

What can the state do to make sure people with IDD can easily get services like health, dental, behavioral and mental health care?

2

How can New York provide more help to family members taking care of their loved ones with IDD?

3

Does abuse in group settings increase during a public emergency? What can be done to make people with IDD safe?

4

Was there an increase in the prescription of medications for people with IDD in congregate settings during the pandemic?

5

How can the state make sure that people with IDD can still get services during an emergency, especially if they are new to the system?

6

Is it fair to make people with IDD follow different rules during a public emergency than everyone else? What rules are safe and fair?

7

Can the Office of the Chief Disability Officer help to improve emergency planning for people with IDD?

8

How can state agencies work together to better understand how to support people with IDD that are getting older?

Conclusion

This report shows that during the pandemic, people with IDD faced many challenges. COVID-19 deaths were one and a half to more than two times higher for people with IDD than the general population. People living in group homes and other congregate settings were four times more likely to test positive and two times more likely to die as compared to the general population.



The state's response impacted more than people with IDD. Family caregivers said they were overwhelmed without support. Providers tried to understand health and safety rules and keep staff and people with IDD safe.

The pandemic was a difficult time for New York, the country and the world. We now have a chance to look back on that first year, identify lessons learned and create solutions to improve the lives of people with IDD in NYS.